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Health Literacy and HIV: Part I What is Health Literacy and Why it Matters

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This program is funded wholly, or in part, by the Government of the District of Columbia, Department of Health, HIV/AIDS, Hepatitis, STD, and TB Administration (HAHSTA)

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Life is a Limited Cultural Event

Life is a combination of a genetic lottery and geographic accident



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Learning Objectives

At the end of this presentation, participants will be able to:

- List two potential negative outcomes for clients who have low health literacy
- List three barriers that can prevent a person from becoming health literate
- Identify two strategies organizations can use to improve health literacy on an individual and/or community scale

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Overview: Health Literacy Basics

- What is health?
- What is health literacy?
- Are health literacy and health education the same?
- Are cultural competence, stigma, and provider bias health literacy concepts?
- Have you received training on health literacy and validated tools to assess it?
- Have you ever assessed the health literacy skills of your patient population?
- What tools have you used to assess health literacy skills?

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What is health?

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

- The World Health Organization¹

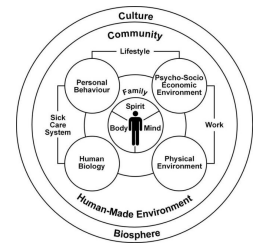
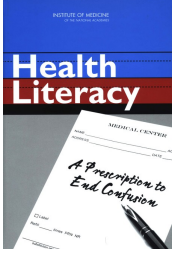


Image courtesy of the Journal Family & Community Health²

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What is Health Literacy?



- **Health literacy** is a **cognitive** and **social skill** that determines the **motivation** and **ability** of individuals to gain access to, understand and use health related information³
- This definition does not make reference to the **cultural literacy** needed to be a wise health care provider and consumer


Image courtesy of National Academies of Science, Engineering and Medicine⁴

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What is Health Literacy? (Cont'd)

- Health literacy is dependent on **individual** and **systemic** factors:
- Communication skills of laypeople and health professionals
- Layperson and professional knowledge of health topics and folkloric medicine
- Culture and language
- Demands of the health care and public health systems
- Demands of the situation/context



Source: adapted from: Misi, W., Nozman, L. An Intersectional approach for improving health literacy for Canada: a discussion paper. Vancouver, Public Health Association of British Columbia, 2012.

Image courtesy of the World Health Organization⁵

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Health Literacy Challenge




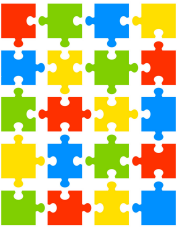
Image courtesy of Harvard University⁶

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Health Literacy Topics

- ✓ Cultural competence
- ✓ Diversity, inclusion
- ✓ Health equity
- ✓ CLAS Standards
- ✓ Culture
- ✓ Discrimination
- ✓ Stigma
- ✓ Bias
- ✓ Prejudice
- ✓ Financial literacy
- ✓ Motivational interview
- ✓ HIV, ART, PrEP
- ✓ Diabetes
- ✓ Hypertension
- ✓ Other health related topics
- ✓ Maternal and child care
- ✓ Environmental health
- ✓ Long term care
- ✓ Communications
- ✓ Social determinants of health
- ✓ Etc.



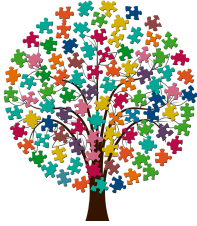
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The Shape of the Health Literacy Puzzle

Health literacy provides the shape of the puzzle

The skills that each individual needs to develop




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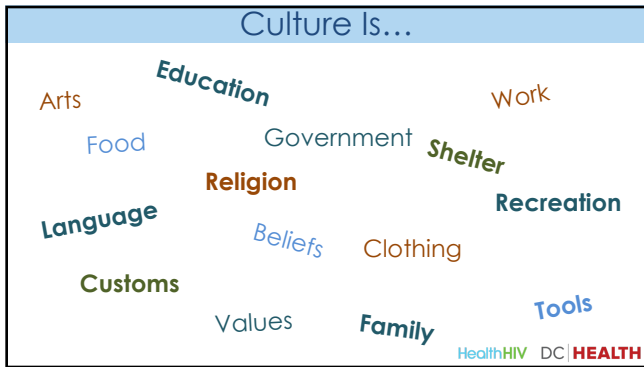
Review: Health Literacy vs Health Education

Health Education	Health Literacy
<ul style="list-style-type: none"> • A public health activity that allows individuals and groups learn about a health topic • Health education does not necessarily address: <ul style="list-style-type: none"> - Personal motivation - Culture/language - Social skills 	<ul style="list-style-type: none"> • Multidimensional • "A person's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course."¹²



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How Does Culture Affect Health?

- How does culture affect health & health literacy?
 - It affects perceptions of health, illness and death
 - Beliefs about causes of disease (the 'evil eye', Voodoo)
 - Approaches to health promotion
 - How illness and pain are experienced and expressed
 - Where patients seek help (family, pharmacy, traditional healer)
 - The types of treatment patients prefer




Image courtesy of Health Top!

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Why Do Patients Need Health Literacy Skills?⁸


Health literacy affects people's ability to:

- **Navigate** the health care system, including filling out forms and locating providers and services
- **Process** information being told to them by their care providers
- **Share** personal information, such as health history, with providers
- **Engage** in self-care and chronic disease management
- **Interpret** mathematical concepts such as probability and risk (key for decision making)
- **Understand** health care instructions, including:
 - Forms, test results, public health advisories, health reports in the media, pamphlets/written materials
- **Recognize** the need for family planning, use of condoms, immunization, etc.

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Prevalence of Low Health Literacy



9 out of 10 adults have **difficulty** using everyday health information⁸

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Health Literacy is Based on Patients'

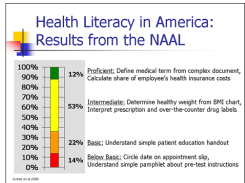
- **Computer Literacy:** use a computer and software to accomplish practical tasks
- **Cultural Literacy:** understand similarities & differences of diverse cultures
- **Language literacy:** understand language in which information is provided
- **Financial literacy:** understand budgeting, expenditure, copays, income, etc.
- **Information literacy:** know when there is a need for information, to locate, evaluate & use it
- **Media literacy:** ability to have an informed, critical understanding of the mass media
- **Visual Literacy:** to understand visual messages

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Prevalence of Low Health Literacy⁹

- Only **12%** of adults in the U.S. have **proficient** health literacy skills
- **14%** of adults (**30 million**) have **below basic** health literacy skills
- **90%** of adults **may lack the skills** needed to manage their health and prevent disease



Health Literacy in America: Results from the NAAL

100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0%

12% Proficient: Define medical term from complex document, Calculate share of employer's health insurance costs

53% Intermediate: Determine healthy weight from BMI chart, Interpret prescription and over-the-counter drug labels

22% Basic: Understand simple patient education handout

14% Below Basic: Circle date on appointment slip, Understand simple pamphlet about pre-test instructions

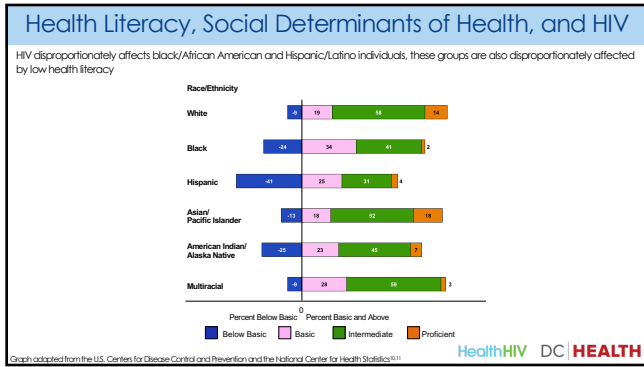
1% Illiterate

© 2007 by NCS

Image courtesy of the Agency for Healthcare Research and Quality!

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Why Do Providers Need to Know Patients' Health Literacy Level?

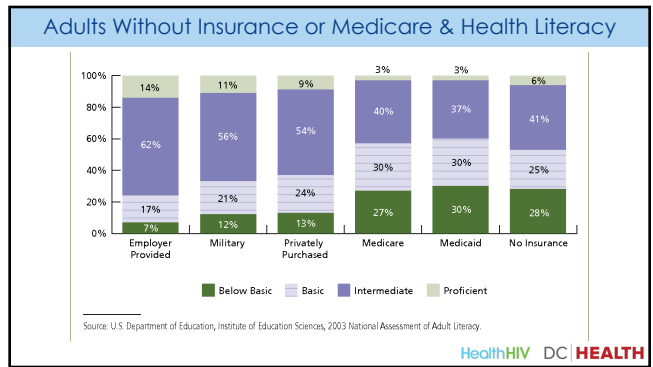
- People with limited health literacy skills often lack knowledge or have misinformation about the body as well as the nature and causes of disease
- Without this knowledge, they may **not** understand the relationship between lifestyle factors such as diet, exercise, use of condoms, and various health outcomes, leading to increased disease risk and worse overall health

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Health Literacy and Health Outcomes¹²

- Low health literacy is associated with poor health outcomes, including:
 - 4x higher health care costs
 - 6x more hospital visits
 - 2-day longer hospital visits
- People with low health literacy are less likely to use preventive services such as health screenings, PrEP, and family planning/condom use
- People with low health literacy are more likely to have chronic conditions - such as high blood pressure, diabetes, and HIV/AIDS - and are less likely to effectively manage these conditions
- It is estimated that low health literacy costs the U.S. economy \$236 billion annually

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Role of Providers in Improving Health Literacy

- The primary responsibility for improving health literacy lies with:
 - public health professionals
 - public health systems
 - **health care providers**
- We must work together to ensure that health information and services can be understood and used by all
- We must engage in skill building with health care consumers and health professionals
- Adult educators can be productive partners in reaching adults with low health literacy

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Strategies to Improve Health Literacy

- Increase your understanding of the importance of health literacy during any interaction between provider and patient
- Learn how to assess health literacy skills of all your patient population
- Learn how to use validated tools to assess health literacy skills in English and Spanish
- Develop a strategy: "CDC Making Health Literacy Real"¹⁰

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Strategies to Improve Health Literacy (cont.)

- Ask open-ended questions to assess the patient's understanding
- Use "Show Back" when teaching how to use a device or perform a particular task
- Use simple language: Say "fats" instead of "lipids"
Say "harmful" instead of "adverse"
- Use graphics/pictures instead of long written instructions
- Provide information in an appropriate language

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Health Literacy and the Social Determinants of Health

- The social determinants of health are the settings in which people grow, work, live, and play¹⁴
- Health literacy is closely related to and affected by the social determinants of health, including:
 - > socioeconomic status
 - > education
 - > race/ethnicity
 - > age
 - > culture
 - > language



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Healthy People 2020 & the Social Determinants¹⁶

- *Healthy People 2020* developed a "place-based" organizing framework, reflecting five key areas of SDOH:
 - > Economic Stability
 - > Education-Language
 - > Social & Community Context-Culture
 - > **Health and Health Care**
 - > Neighborhood and Built Environment



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Health Literacy and the Social Determinants of Health¹⁶

- Health literacy is an important determinant of health **inequities** across racial/ethnic minorities
- The definition of health literacy is evolving from a focus on clinical risk to a focus on health literacy as a **cultural** and **social** skill
- Researchers observe an array of sociodemographic differences in the **risk** of **low** health literacy in the US
- Low health literacy is more **prevalent** among older adults, racial/ethnic minorities, and low socioeconomic status groups
- Limited English Proficiency (LEP) is another key **barrier** to health literacy, also associated with poorer health status in Latinos

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Health Literacy, Social Determinants of Health, and HIV

- HIV/AIDS disproportionately impacts high-risk groups
- Social determinants of health and low health literacy are factors that work together to reduce access to prevention, testing, and treatment
- As the HIV/AIDS population ages and lives longer with the disease, the issue of low health literacy among older adults is of critical importance to HIV/AIDS care providers



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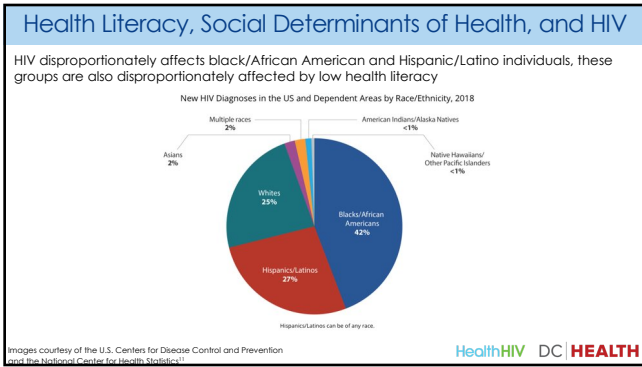
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Health Literacy, Social Determinants of Health, and HIV

- As of 2016, 1.1 million individuals were living with HIV in the U.S., an estimated 14% (1 in 7) were unaware of their HIV status¹¹
- Blacks/African Americans face the most severe burden of HIV compared with other races and ethnicities
 - > In 2018, Black/African American individuals accounted for 42% of new HIV diagnoses, but only 13% of the U.S. population¹¹
- Hispanic/Latino individuals are also disproportionately affected, accounting for 27% of new diagnoses and 18% of the total U.S. population¹¹
- Among men who have sex with men (MSM) - the sub-population most-affected by HIV, accounting for 69% of new diagnoses in 2018 - Black/African American MSM accounted for 37% of new diagnoses and Hispanic/Latino MSM accounted for 30%¹¹

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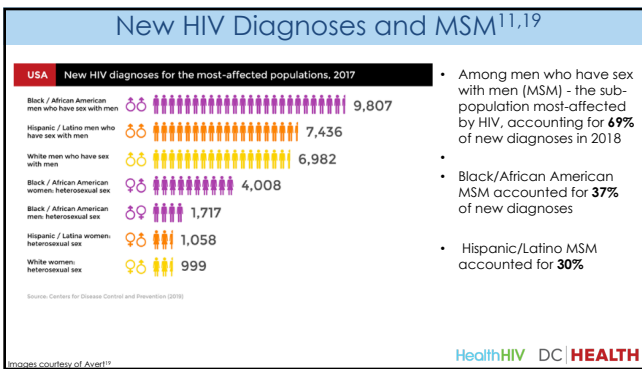
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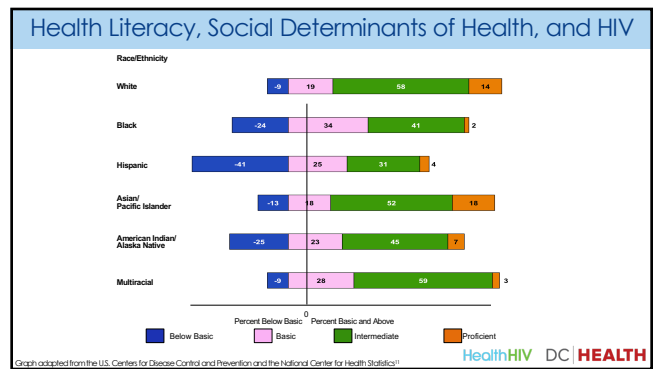
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- ### Health Literacy, Social Determinants of Health & HIV^{17,18}
- The rate of new HIV infections among Black women was 20 times that of White women
 - 86% of HIV infections in women were attributed to heterosexual contact
 - Social determinants are influential factors of women's sexual behavior decision-making, and their HIV risks
 - Health literacy is closely **related** to socioeconomic status and education, thereby increasing **risk** for **low** health literacy HIV/AIDS patients
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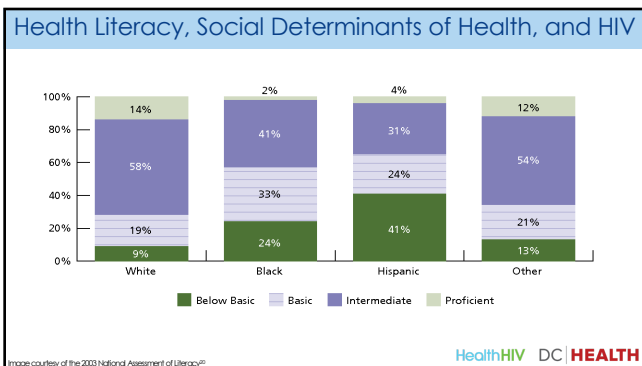
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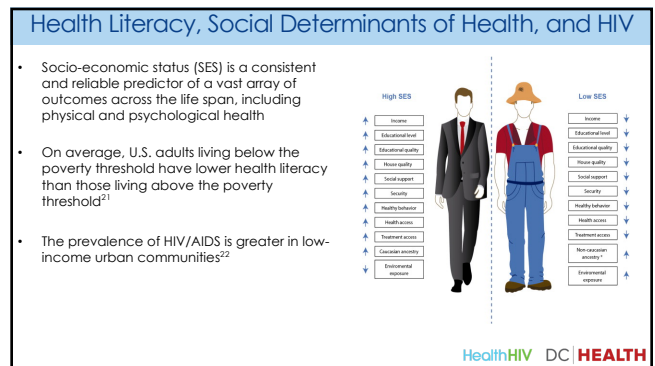
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Health Literacy, Social Determinants of Health, and HIV

- The HIV epidemic is now concentrated in socially marginalized and disenfranchised communities^{1,22}
- Health disparities in this epidemic are striking, with most HIV infections occurring in sexual minorities and communities of color²²
- HIV transmission is a biological event that is entirely dependent on social context and behavioral practices
- Poverty, discrimination, inequality and other social conditions facilitate HIV transmission by influencing local HIV prevalence as well as an individual's risk behaviors

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Health Literacy and Health Outcomes for PLWH

Health Literacy and Health Outcomes

Image courtesy of AECOP adapted from Paschke-Ottow & Wolf²³

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Health Literacy and Health Outcomes for PLWH²⁶

- 83% of patients with low health literacy and education do not understand their viral load
- 71% of patients with low health literacy and high education, do not fully understand their viral load
- 35% of patients with low health literacy and low education, practice more unsafe sex because of new HIV treatment options

Image courtesy of the American Journal of Preventive Medicine²⁶

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Health Literacy and Older Adults Living with HIV

HIV and Aging

- By 2030 the proportion of the US population aged 65 and older will double from 39 million to about 71 million
- People living with HIV are living longer with a diverse array of aging related conditions

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Health Literacy and Older Adults Living with HIV

- As of 2015, an estimated 47% of individuals living with HIV in the U.S. were aged 50 and older²⁸
- Older U.S. adults have lower average health literacy skills and are more likely to have below basic health literacy skills²¹
- Individuals living with long-term HIV infection exhibit many clinical characteristics commonly observed in aging:
 - multiple chronic diseases or conditions
 - the use of multiple medications
 - changes in physical and cognitive abilities
 - increased vulnerability to stressors
 - Etc.

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People living with HIV by Age, 2015, U.S.

Age Group	Under 50 years of age	50 years of age and older
Under 18	2,322	-
18-19	721	-
20-24	4,959	-
25-29	30,812	-
30-34	65,540	-
35-39	76,656	-
40-44	88,370	-
45-49	103,583	-
50-54	-	146,340
55-59	-	171,372
60-64	-	131,430
65 and over	-	81,438
70-74	-	70,644

Image courtesy of the Centers for Disease Control and Prevention²⁸

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Health Literacy and HIV: Research³⁰

- Low HL is a major problem with a growing number of studies linking it to poor health outcomes including:
 - Higher hospitalization rates
 - Emergency department utilization and
 - Poorer disease outcomes for conditions such as HIV
- Health literacy has previously been operationalized as general functional literacy, but has not included content knowledge about HIV disease and treatment

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patients with low HEALTH LITERACY...



Image courtesy of the Centers for Disease Control and Prevention³¹

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Health Literacy and HIV: Research³²

- A study based on semi-structured interviews with people living with HIV concluded that:
 - Most understood that HIV degrades the immune system
 - None could explain the nature of a virus or the mechanism of (ARV) drug action
 - Fewer than half accurately reported that it is desirable to have a high CD4+ cell count and low viral load
 - A minority understood the concept of drug resistance

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Health Literacy and HIV: Research³²

- The same study also found:
 - Some patients believed that periodic treatment interruption was beneficial
 - Some patients believed they should not take ARVs when they used alcohol or illicit drugs
 - Respondents generally had very limited, and often inaccurate biomedical understanding of HIV
 - Some patients did not understand that the consequences of erratic adherence include not only the possibility of treatment failure, but the development of a drug resistant strain of the virus, and increased probability of transmitting HIV to others

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Health Literacy, HIV, ART, and PrEP³³

- Antiretroviral therapy (ART) has made it possible for PLWH to achieve viral suppression and live longer lives
- However, many PLWH are not achieving optimal treatment outcomes, due to limited health literacy skills
- Disparity between the number of people diagnosed with HIV, and the number of people achieving viral suppression may be attributed to multiple factors, including healthcare access, and treatment costs, but low health literacy plays a key role

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Health Literacy, HIV, ART, and PrEP³³

- Health literacy is crucial to the successful treatment of HIV for multiple reasons, including:
 - The chronic nature of HIV
 - The need for vigilance of health and risk behaviors
 - The need for strict adherence to treatment regimens

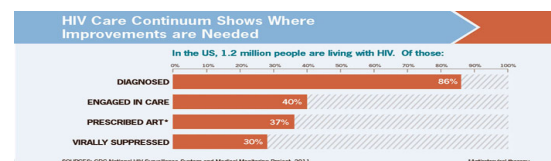



Image courtesy of the HIV.gov³⁴

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Health Literacy, HIV, ART, and PrEP³³

- Low health literacy can lead to:
 - Disease-related complications
 - More symptoms
 - More difficulty understanding health-related instructions
 - Poor adherence to HIV medications
 - Not achieving optimal treatment outcomes
 - Choose the wrong ART
 - Lack of understanding about PrEP
- Future research should include efforts to determine cultural issues to develop culturally appropriate interventions




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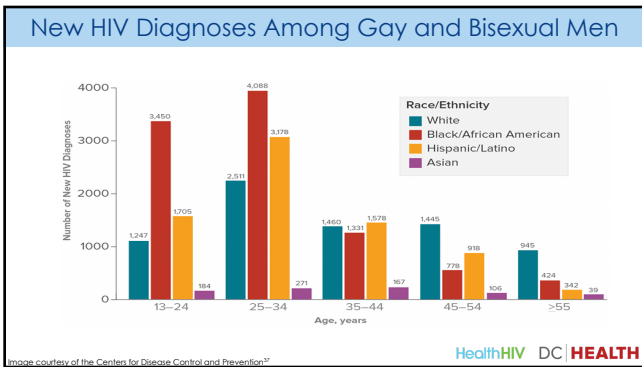
Health Literacy and HIV: LGBTQ Sex Education³⁶

- Data from sources including the CDC show how few sex education programs are inclusive of LGBTQ youth
- Only 19% of U.S. secondary schools provide curricula or supplementary sex education materials that are LGBTQ-inclusive
- Fewer than 5% of LGBT students have health classes that included positive representations of LGBT-related topics



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Conclusion

- Health literacy is a cognitive and social skill that determines the motivation and ability of individuals to gain access to, understand and use health related information
- Health literacy matters to patients and providers because it can affect disease risk and health outcomes
- Social determinants of health and low health literacy are factors that work together to negatively impact health outcomes and increase disease risk
- Low health literacy is a barrier to HIV prevention, testing, and treatment services that disproportionately impacts vulnerable populations³⁸
- Health Literacy is at the core of everything we do

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Health Literacy and HIV: Part II Assessing Health Literacy

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Learning Objectives

At the end of this presentation, participants will be able to:

- List three validated tools to assess health literacy
- List three additional skills that play a role in acquiring health literacy and that become barriers that can prevent a person from becoming health literate
- Mentioned one reason why use a validated tool to assess health literacy

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Overview

- What is health literacy and how does it affect health outcomes? (Recap)
- Barriers to health literacy
- Strategies to assess health literacy
- Validated health literacy assessment **tools**

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Review: What is Health Literacy?

- **Health literacy** is a **cultural, cognitive** and **social skill** that determines the motivation and ability of individuals to gain access to, understand and use health related information¹
- **Health literacy** includes numeracy skills.
 - For **example**, calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels **all** require numeracy **skills**

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Review: Health Literacy vs Health Education



... a multidimensional concept



« A person's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course»

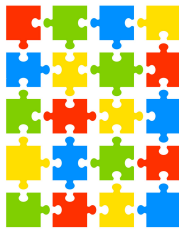
WHO Health Literacy, The solid facts, March 2016

- Health education is a public health **activity** that allows individuals and groups learn about a health topic
- Health education does not necessarily address:
 - Personal motivation
 - Culture/language
 - Social skills
 - Stigma, bias, discrimination

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Some Health Literacy Topics

- ✓ Cultural competence
- ✓ Diversity, inclusion
- ✓ Health equity
- ✓ CLAS Standards
- ✓ Culture
- ✓ Discrimination
- ✓ Stigma
- ✓ Bias
- ✓ Prejudice
- ✓ Financial literacy
- ✓ Motivational interview
- ✓ HIV, ART, PrEP
- ✓ Diabetes
- ✓ Hypertension
- ✓ Other health related topics
- ✓ Maternal and childcare
- ✓ Environmental health
- ✓ Long term care
- ✓ Communications
- ✓ Social determinants of health
- ✓ Etc.

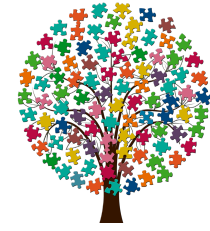


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The Shape of the Health Literacy Puzzle

Health literacy provides the shape of the puzzle

The skills that each individual needs to develop



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Review: Why Does Health Literacy Matter?

- People with low health literacy skills often lack knowledge or have misinformation about the body as well as the nature and causes of disease
- Without this knowledge, they may **not** understand the relationship between lifestyle factors such as diet, exercise, use of condoms, and various health outcomes, leading to **increased** disease **risk** and worse overall health

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Review: Why Does Health Literacy Matter?

In addition, low health literacy affects individuals' ability to:

- **Navigate** the health care system, including filling out forms, locating providers & services
- **Process** information being told to them by their care providers
- **Share** personal information, such as health history, with providers
- **Engage** in self-care and chronic disease management
- **Interpret** mathematical concepts such as probability and risk (key for decision-making)
- **Understand** health care instructions, including:
 - Forms, test results, public health advisories, health reports in the media, pamphlets/written material
- **Recognize** the need for family planning, use of condoms, immunization, etc.³

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Review: Why Does Health Literacy Matter?

Poor Health Literacy Leads to:

- Lower use of preventive care services
- Greater use of emergency care
- Frequent hospitalizations
- Poor self-care management
- Unhealthy behaviors
- Poor health outcomes & premature deaths
- Higher health care costs (loss of \$238 billion/yr)

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Skills that Influence Health Literacy

- Communication (pronunciation, verbalization, LEP)
- Comprehension (prose/reading, problem solving)
- Quantitative/Numeracy
- System navigation (intentionally complex?)
- Health information seeking
- Decision making/critical thinking
- Cultural background, beliefs, bias, stigma
- Need for assistance (When? Why? Primary provider?)



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Skills that Influence Health Literacy (Cont'd)

- **Computer Literacy:** the ability to use a computer to accomplish practical tasks
- **Cultural Literacy:** understanding of the similarities and differences between diverse cultures
- **Language Literacy:** understanding of the language in which information is provided
- **Financial literacy:** understanding of financial concepts, such as budgeting, expenditures, copays, income, etc.
- **Information Literacy:** when information is needed, & how to locate, evaluate, and use it to accomplish tasks
- **Media Literacy:** the ability to form a critical understanding of mass media ("Fake News")
- **Visual Literacy:** the ability to understand visual messages

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How Does Culture Affect Health & Health Literacy?

- How does culture affect health & health literacy?
 - It affects perceptions of health, illness and death
 - Beliefs about causes of disease (the 'evil eye', Voodoo)
 - Approaches to health promotion
 - How illness and pain are experienced and expressed
 - Where patients seek help (family, pharmacy, traditional healer)
 - The types of treatment patients prefer



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Barriers to Health Literacy

Low **literacy** skills are one of the most critical barriers to health literacy in the U.S.

- 1 in 5 U.S. adults have low literacy skills, meaning they are unable to compare and contrast, paraphrase, or make inferences based on written information⁴

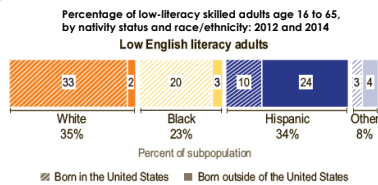


Image courtesy of the National Center for Education Statistics⁴

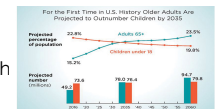
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Barriers to Health Literacy (Cont'd)

Other barriers to health literacy include:

- Population changes (aging, migration)
- Cultural values and understanding of health
- Technology gaps
- Inability to understand health information (learning disabilities)
- Limited English proficiency (LEP)
- Difficulties navigating the health care environment
- Compromised quality of care when patient's health literacy is inadequate



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National Action Plan to Improve Health Literacy⁵

- Seeks to engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multi-sector effort to improve health literacy
- The plan is based on the principles that:
 - (1) Everyone has the **right** to health information that helps them make informed decisions and
 - (2) Health services should be delivered in ways that are **understandable** and beneficial to health, longevity, and quality of life

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How to Improve Health Literacy³

1. **Assess** health literacy skills of the intended users of health information and services
2. **Develop** materials tailored to users' culture and health literacy level
3. Beyond demographics, culture, and language, consider the **communication** capacities of the intended users
 - Approximately 1 in 6 people in the U.S. has a communication disorder (speech & sound, autism, brain injury, etc.), resulting in unique challenges



Know your audience!

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How to Improve Health Literacy (Cont'd)³

- Health information must be relevant to the intended users' **health literacy** skills, and **social** and **cultural** contexts
- Talk to members of the target population before you develop health-related materials and messages to determine:
 - Cultural values and background
 - Native or preferred language
 - Health literacy skills
- Use validated tools to assess health literacy skills
- Pilot test messages with targeted groups to assess comprehension and effectiveness

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How to Improve Health Literacy (Cont'd)³

- Acknowledge cultural factors including:
 - race, ethnicity,
 - language, nationality
 - religion, beliefs
 - age, gender, sexual orientation
 - income level, socioeconomic status, occupation, etc.
- Culture may impact:
 - Accepted roles of men and women
 - Value of traditional medicine versus Western medicine
 - Favorite and forbidden foods (pork, milk products, alcohol)
 - Manner of dress codes
 - Whether touching or proximity is permitted in specific situations



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How to Improve Health Literacy (Cont'd)³

- Promote culturally tailored education events and materials (electronic and hard copy)
- Support legislation to make public health information more accurate and **culturally** relevant
- Support health science & biology in school curriculums
- Support ESL and adult education programs
- Develop partnerships with CBOs, FBOs and private businesses
- Partner with media to promote programs that increase health literacy (TV, radio, newspapers)

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Strategies to Improve Health Literacy: Providers

- Use validated Health Literacy Assessment tools to **assess** all patients
- Assess, understand and **respect** patients' cultural values
- Frequent review **understanding** of instructions with patients
- Ensure that forms and handouts are in the patient's **language**
- Allow **time** for explanations and questions
- Using **plain**, nonmedical language



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Strategies to Improve Health Literacy: Organizations⁶

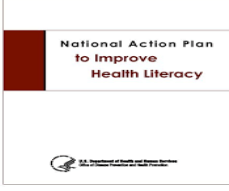
- Ensure that health literacy is integrated into **all** organizational activities
- Provide **training** and education to employees
- Ensure health literacy is addressed in **strategic** and operational planning
- Develop appropriate **measures** to evaluate specific health literacy goals
- Include clients/patients in **planning** interventions to address health literacy gaps

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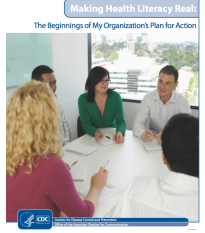
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How to Improve Health Literacy: Resources

- U.S. Centers for Disease Control and Prevention: "Making Health Literacy Real"⁷
- National Action Plan to Improve Health Literacy⁵



National Action Plan to Improve Health Literacy




Making Health Literacy Real: The Beginnings of My Organization's Plan for Action

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Tools to Assess Health Literacy

- What is an assessment tool?
 - An assessment tool is used to evaluate the cognitive and social skills of an individual or target population
 - Health literacy assessment tools are screening instruments used to determine the level of health literacy skills of individuals
- Common use of a tool to assess health literacy:
 - For **all** new patients
 - When there are developmental changes
 - If there is a new behavioral or mental health diagnosis
 - Etc.



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Why Assess Health Literacy?


- Knowing how to assess a patient's ability to understand health information is essential in order to identify the most vulnerable patients who need **help** due to their **low** health literacy skills
- That is why it is important to teach future generations of health care providers:
 - To assess health literacy skills
 - To address cultural and linguistic gaps
 - To communicate effectively both orally and in writing with patients who have **low** health literacy skills

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Screening tools

- A screening tool is a checklist or questionnaire used by health professionals to assess knowledge and understanding of health related issues
- A screening tool may be used by:
 - Physicians
 - Nurses
 - Social workers
 - Health educators
 - Trained paraprofessionals
 - Public health professionals
 - Other medical professionals



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What is a Validated tool?

- A validated screening tool is an instrument that has been psychometrically tested for:
 - **Reliability:** The ability of the instrument to produce consistent results
 - **Validity:** The ability of the instrument to produce true results
 - **Sensitivity/Normativity:** The probability of correctly identifying a patient with the condition
 - **Cultural and Linguistic Tailoring:** Not just translated from one language to another
- A non-validated tool is one that has **not** undergone testing as noted above, and might be a home-grown tool developed by a hospital, health care facility, or other institution

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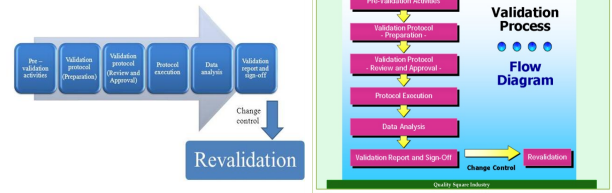
Why Use a Validated Tool to Assess Health Literacy?

- **Reliability** ensures the tool will yield the same results when administered repeatedly
- **Validity** means the test measures what it is supposed to measure
- **Sensitivity/normativity** means you can compare one patient's answers to the answers of other patients in the same group as them
- **Culturally and linguistically tailored** tools avoid bias, which occurs when a measure only applies to certain segments of the population

Results obtained with non-validated tools cannot be compared with other institutions, and do **not** have scientific validity

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Validation process



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Who Should Assess Health Literacy?

- Health care **providers** play a major role in assessing health literacy skills and providing leadership to meet the challenge of low health literacy in our society
- Additionally, health care providers need to:
 - Know how to implement strategies to increase health literacy
 - Create patient-centered approaches
 - Provide a shame-free environment
 - Enhance health literacy not only for patients with **low** health literacy skills, but for **all** patients

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Behaviors of Patients With Low Health Literacy

- Patients with low health literacy skills are masters at concealing their deficit, so it is difficult to realize that a problem exists
- Some excuses are:
 - "I don't have my glasses"
 - "I'm too tired to read"
 - "I'll read this when I get home"
- Poor readers often lift text closer to their eyes, or point to the text with a finger while reading
- Patients with low health literacy also:
 - Often **miss** appointments
 - Make **errors** regarding their medication

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How Frequently Should Health Literacy Be Assessed?

- The frequency to assess patient's HL skills varied depending upon your program and patients health status
- Health literacy skills can increase or decrease over time
- Socio-economic factors and other social determinants of health may cause changes in health literacy skills
- Changes in education and English language proficiency may influence health literacy skills
- **Illnesses** affecting the brain or mental health, increased **age**, and memory loss are factors that may cause a decrease in health literacy skills

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Concerns Regarding Health Literacy Testing

- Some patients with low health literacy skills already feel stigmatized and fear exposure, and may elect to go elsewhere for medical services if a health literacy test becomes part of routine care
- Only about **20%** of tools are validated for **Spanish** speaking populations
- Some providers and organizations may need **technical** assistance to improve utilization of limited human & financial resources
- The main concern is to know the health literacy skill level of your patients, which will influence their **understanding** and compliance

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Concerns Regarding **NOT** Assessing Health Literacy

9 out of 10 adults have difficulty using everyday health information³

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Concerns Regarding **NOT** Assessing Health Literacy

patients with low **HEALTH LITERACY...**

- Are more likely to visit an **EMERGENCY ROOM**
- Have more **HOSPITAL STAYS**
- Are less likely to follow **TREATMENT PLANS**
- Have higher **MORTALITY RATES**

www.cdc.gov/phpr

Image courtesy of the U.S. Centers for Disease Control and Prevention⁴

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Common Tools to Assess Health Literacy

- Rapid Estimate of Adult Literacy in Medicine (REALM)
- Rapid Estimate of Adult Literacy in Medicine - Revised (REALM-R)
- Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen)
- Test of Functional Health Literacy in Adults (TOFHLA/TOFHLiD (Spanish version))
- Short Test of Functional Health Literacy in Adults (S-TOFHLA)
- Newest Vital Sign (NVS)
- Short Assessment of Health Literacy – Spanish & English (SAHL – S&E)
- Short Assessment of Health Literacy for Spanish-Speaking Adults (SAHLSA)

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Common Tools to Assess Health Literacy (Cont'd)

- Medical Term Recognition Test (METER)
- Brief Health Literacy Screening Tool (BRIEF)
- Brief Estimate of Health Knowledge and Action – HIV Version (BEHKA-HIV)
- Single Item Literacy Screener (SILS)

REALM
Rapid Estimate of Adult Literacy in Medicine

- Word recognition test
- Quick and easy to administer
- Participant reads each word and lists. Scored on number of words recognized correctly.
- 0-18 correct = 3rd grade
- 19-44 correct = 4th-6th grade
- 45-60 correct = 7th-8th grade
- 61-66 correct = high school
- Does not require a key to know the word's meaning.

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Rapid Estimate of Adult Literacy in Medicine (REALM)⁹

- 66-item** health-related word recognition test arranged in order of increasing difficulty
- Provides a reading level grade estimate for patients that read below a 9th- grade level
- Average administration time: **3-6 minutes**
- Word-recognition tests are useful for predicting general reading ability in English
- Used in health literacy research settings

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REALM⁹

REALM

0-18 correct = ≤ 3rd grade
 19-44 correct = 4th-6th grade
 45-60 correct = 7th-8th grade
 61-66 correct = high school

List 1	List 2	List 3
tat	fatigue	allergic
flu	pelvic	menstrual
pill	jaundice	testicle
dose	infection	colitis
eye	exercise	emergency
stress	behavior	medication
smear	prescription	occupation
nerves	notify	sexually
germs	gallbladder	alcoholism
meals	calories	irritation
disease	depression	constipation
cancer	miscarriage	gonorrhea
caffeine	pregnancy	inflammatory
attack	arthritis	diabetes
kidney	nutrition	hepatitis
hormones	menopause	antibiotics
herpes	appendix	diagnosis
seizure	abnormal	potassium
bowel	syphilis	anemia
asthma	hemorrhoids	obesity
rectal	nausea	osteoporosis
insect	directed	impetigo

Davis, Fam Med, 1993

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Summary: REALM⁹

Description	<ul style="list-style-type: none"> A 66-item health-related word recognition test arranged in order of increasing difficulty Provides a reading level grade estimate for patients that read below a 9th-grade level Average administration time: 3-6 min
Measurement	<ul style="list-style-type: none"> 0-18: At or below 3rd-grade reading level/unable to read low health literacy materials 19-44: 4th to 6th-grade reading level/able to read most low health literacy materials, may be unable to read prescription labels 45-60: 7th to 8th-grade reading level/use low health literacy materials 61-66: High school reading level/able to read most patient education materials
Strengths	<ul style="list-style-type: none"> Word-recognition tests are useful for predicting general English reading ability Used in health literacy research settings
Limitations	<ul style="list-style-type: none"> Does not measure comprehension skills or numeracy
Location	<ul style="list-style-type: none"> Available for purchase from Terry C. Davis, PhD: tdavis@lsuhsc.edu

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Rapid Estimate Adult Literacy in Medicine Revised (REALM-R)¹⁰

- 11-item** word recognition test, used to identify people at risk for low literacy skills¹¹
- Words that appear on this test are:
Fat, Flu, Pill, Osteoporosis, Anemia, Colitis, Allergic, Fatigue, Constipation, Jaundice, Directed
- "Fat," "flu," and "pill" are not scored and are positioned at the beginning of the REALM-R to decrease test anxiety and enhance confidence
- Point to the first word, ask the person read the 11 words out loud
- Average administration time: **2-3 minutes**

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REALM-R¹⁰

- Visual Acuity, ask the person to wear their glasses for the test
- The word list should be set in 18-point font
- Dictionary pronunciation is the scoring standard
- Count a word as correct if it is pronounced correctly and no additions or deletions have been made to the beginning or ending of the word
 - Words pronounced with a dialect or **accent** should be counted as **correct**, provided there are no additions or deletions to the word
- Particular attention should be paid to persons for whom English is a second language
- Limitation:** The REALM-R can only be used for persons who read English, it has **not** been validated in other languages

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REALM-R

Short REALMs: REALM-R

REAL-R (2002)

- Correlations: REALM (.72), WRAT-R3 (.64)
- Score of ≤ 6 = risk for low literacy
- 11 words (only 8 are scored) – fat, flu, and pill are not scored
 - Fat
 - Flu
 - Pull
 - Allergic
 - Jaundice
 - Anemia
 - Fatigue
 - Directed
 - Colitis
 - Constipation
 - Osteoporosis

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Summary: REALM-R¹⁰

Description	<ul style="list-style-type: none"> The word-recognition REALM test was shortened from 66 items to 8 items Average administration time: 2 - 3 min
Measurement	<ul style="list-style-type: none"> Score ≤ 6 indicates risk for low health literacy
Strengths	<ul style="list-style-type: none"> Short administration time Additional words can be added while maintaining the 2-minute administration time, allowing for development of a more disease-specific test
Limitations	<ul style="list-style-type: none"> Older adults and minorities (two groups disproportionately affected by low health literacy) were underrepresented in the study validating the REALM-R Little is known about utility in research and clinical settings
Location	<ul style="list-style-type: none"> Available for purchase from Terry C. Davis, PhD: tdavis@lsuhsc.edu

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Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen)¹²⁻¹³

- Validated tool to screen youth ages 10-17
- 1 page, **66 items**
- Average administration time: **3-5 minutes**
- Adolescents are asked to say words out loud
- Raw score is the total number of correctly pronounced words

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REALM-Teen¹²

REALM-Teen

Scoring

- Raw score = total number of correctly pronounced words
- Dictionary pronunciation is the scoring standard

Raw Score	Grade Range Equivalent	Literacy Skills
0-37	≤ 3 rd Grade	These adolescents will have a 5 fold likelihood of reading below grade level. They may be at risk of school failure.
38-44	4 th - 5 th Grade	
45-58	6 th - 7 th Grade	Will struggle with most patient education materials; may have skills to pass GED.
59-82	8 th - 9 th Grade	
83-86	≥ 10 th Grade	Will be able to read most patient education materials.

eye	fever	nutrition
pill	pimple	alcoholism
fat	virus	antibiotic
skin	colorless	complications
throat	allergy	delinquency
blood	marijuana	penicillin
weight	pelvic	puberty
stress	asthma	menstrual
death	emergency	pneumonia
liquid	infection	constipation
disease	exercise	diagnosis
drug	medicine	nausea
mouth	violence	acne
ounce	prevention	anemia
heart	suicide	hepatitis
risk	depression	adolescent
diet	prescription	bulimia
teaspoon	abnormal	fatigue
period	injury	emorexia
cancer	ointment	tetanus
stomach	seizure	bronchial
headache	diabetes	obesity

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Summary: REALM-Teen¹²⁻¹³

Description	<ul style="list-style-type: none"> Validated tool to screen youth ages 10-17 66-items, score based on correct pronunciation Average administration time: 3-5 mins
Measurement	<ul style="list-style-type: none"> 0-105: Below 3rd-grade reading level 106-139: 4th-5th-grade reading level 140-169: 6th-7th-grade reading level 170-183: 8th-9th-grade reading level 184-213: 10th-grade or above
Strengths	<ul style="list-style-type: none"> Short administration time Additional words can be added while maintaining the 2-minute administration time, allowing for development of a more disease-specific test
Limitations	<ul style="list-style-type: none"> Score is based on correct pronunciation, need to account for dialect/accent of patient
Location	<ul style="list-style-type: none"> Available for purchase from Terry C. Davis, PhD: tdavis@tsuhsdc.edu

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Test of Functional Health Literacy in Adults (TOFHLA)¹⁴

Two-part assessment:

- Part 1:** Participants are provided with medical information or instructions (e.g., instructions on a prescription label or instructions about preparation for a diagnostic procedure), participants review the information answer questions that test their **understanding**
- Part 2:** Participants are given passages of text about medical topics with certain **words** replaced with blank spaces, and must fill in the blank spaces using words selected from a multiple-choice list (based on the Cloze Method)
- Average administration time: **22-25 minutes**

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TOFHLA

Numeracy:

Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995)

GARFIELD IM 16 Apr 93
 FF9-41862 Dr. LUBIN, MICHAEL

DOXYCYCLINE 20/0
 100 mg

Take medication on empty stomach one hour before or two to three hours after a meal unless otherwise directed by your doctor.

02 11 (0 of 20)

Interviewer: If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it?

Image courtesy of the Feinberg School of Medicine, Northwestern University¹²

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Summary: TOFHLA¹⁴

Description	<ul style="list-style-type: none"> TOFHLA reduced from 17 numeracy items and 3 prose passages 4 numeracy items and 2 prose passages Average administration time: 8 – 12 minutes
Measurement	<ul style="list-style-type: none"> 0-53: Inadequate health literacy 54-66: Marginal health literacy 67-100: Adequate health literacy
Strengths	<ul style="list-style-type: none"> Indicator of a patient's ability to read and understand health-related text and numerical equations Tested on a variety of populations (young, elderly) Shortened administration time compared with TOFHLA
Limitations	<ul style="list-style-type: none"> Still longer administration time than other tools
Location	<ul style="list-style-type: none"> Available for purchase from http://www.peppercombooks.com

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Short Test of Functional Health Literacy in Adults (S-TOFHLA)¹⁶⁻¹⁷

- (S-TOFHLA) is a shortened version of the TOFHLA
 - Reduced from 17 numeracy items and 3 prose passages to **4 numeracy** items and **2 prose** passages
- Average administration time: **8 – 12 mins**

PASSAGE A
 Your doctor has sent you to have a _____ X-ray.
 a. chest
 b. stomach
 c. kidney
 d. spine

You must have an _____ stomach when you take the _____
 a. empty a. 1/2
 b. full b. 1/4
 c. empty c. 1/2
 d. full d. 1/4

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S - TOFHLA

PASSAGE A
Your doctor has sent you to have a _____ X-ray.

a. stomach
b. diabetes
c. stitches
d. germs

You must have an _____ stomach when you come for _____.

a. asthma
b. empty
c. insect
d. anemia

The X-ray will _____ from 1 to 3 _____ to do.

a. take
b. view
c. talk
d. look

a. beds
b. brains
c. hours
d. diets

THE DAY BEFORE THE X-RAY.
For supper have only a _____ snack of fruit, _____ and jelly, with coffee or tea.

a. little
b. broth
c. attack
d. nausea

a. toes
b. throat
c. toast
d. thigh

Parker, J Gen Intern Med, 1995

Scoring:

0-16:
Inadequate func. HL

17-22
Marginal func. HL

23-36
Adequate func. HL

109

Summary: S-TOFHLA¹⁶⁻¹⁷

Description	<ul style="list-style-type: none"> TOFHLA reduced from 17 numeracy items and 3 prose passages 4 numeracy items and 2 prose passages Average administration time: 8–12 minutes
Measurement	<ul style="list-style-type: none"> 0-53: Inadequate health literacy 54-66: Marginal health literacy 67-100: Adequate health literacy
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Limitations	<ul style="list-style-type: none"> Still longer administration time than other tools
Location	<ul style="list-style-type: none"> Available for purchase from http://www.peppercombooks.com

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Newest Vital Sign (NVS)¹⁸

- 6-item** assessment measuring reading comprehension of a nutrition label from an ice cream container
 - Patients may refer to the label while answering questions about it
- Average administration time: **3-6 mins**
- Tests for numeracy, reading ability, and comprehension skills
- Available in **English** and **Spanish**
- In clinical settings, allows providers to adapt their communication practices to the patient's health literacy level
- Correlates with TOFHLA
- More sensitive to patients with low health literacy than other functional health literacy assessments

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NVS

Numeracy:
Newest Vital Sign (NVS) (Weiss et al., 2005)

Nutrition Facts		% Daily Value*
Serving Size	1/2 cup	4
Amount per serving		
Calories	250	Fat Cal 120
<hr/>		
Total Fat 13g		26%
Sat Fat 9g		40%
Cholesterol 28mg		12%
Sodium 55mg		2%
Total Carbohydrate 30g		12%
Dietary Fiber 2g		
Sugars 23g		
Protein 4g		8%

*Percent Daily Values (DV) are based on a diet of 2,000 calories daily. Your daily values may be higher or lower depending on your calorie needs.
Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Interviewer: If you eat the entire container, how many calories will you eat?

Image courtesy of the Feinberg School of Medicine, Northwestern University¹⁷

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NVS

<table style="font-size: x-small; border-collapse: collapse;"> <tr> <td colspan="2">Nutrition Facts</td> <td style="text-align: right;">% Daily Value*</td> </tr> <tr> <td>Serving Size</td> <td>1/2 cup</td> <td>4</td> </tr> <tr> <td>Amount per serving</td> <td></td> <td></td> </tr> <tr> <td>Calories 250</td> <td>Fat Cal 120</td> <td></td> </tr> <tr> <td colspan="3"><hr/></td> </tr> <tr> <td>Total Fat 13g</td> <td></td> <td style="text-align: right;">26%</td> </tr> <tr> <td>Sat Fat 9g</td> <td></td> <td style="text-align: right;">40%</td> </tr> <tr> <td>Cholesterol 28mg</td> <td></td> <td style="text-align: right;">12%</td> </tr> <tr> <td>Sodium 55mg</td> <td></td> <td style="text-align: right;">2%</td> </tr> <tr> <td>Total Carbohydrate 30g</td> <td></td> <td style="text-align: right;">12%</td> </tr> <tr> <td>Dietary Fiber 2g</td> <td></td> <td></td> </tr> <tr> <td>Sugars 23g</td> <td></td> <td></td> </tr> <tr> <td>Protein 4g</td> <td></td> <td style="text-align: right;">8%</td> </tr> </table> <p style="font-size: x-small;">* Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs. Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.</p>	Nutrition Facts		% Daily Value*	Serving Size	1/2 cup	4	Amount per serving			Calories 250	Fat Cal 120		<hr/>			Total Fat 13g		26%	Sat Fat 9g		40%	Cholesterol 28mg		12%	Sodium 55mg		2%	Total Carbohydrate 30g		12%	Dietary Fiber 2g			Sugars 23g			Protein 4g		8%	<p style="font-size: x-small;">READ TO SUBJECT: This information is on the back of a container of ice cream.</p> <p style="font-size: x-small;">QUESTIONS:</p> <p>1. If you eat the entire container, how many calories will you eat? Answer: 1,000 is the only correct answer.</p> <p>2. If you are allowed to eat 80 g of carbohydrates in a snack, how much ice cream could you eat? Answer: Any of the following is correct: 1/3 cup or any amount up to 1 cup 1/2 half the container Half of patient answers "2 servings," ask "How much ice cream could that be if you were to measure it?"</p> <p>3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 2g of saturated fat each day, which amount is a serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? Answer: 13 is the only correct answer.</p> <p>4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? Answer: 10% is the only correct answer.</p> <p style="font-size: x-small;">*Please read the following instructions: Respond "yes," "no," "more," and "less." 5. Is it safe for you to eat this ice cream? Answer: No</p> <p>6. (Ask only if the patient responds "no" to question 5.) Why not? Answer: (Respond to the general "no.")</p> <p style="text-align: center; font-size: x-small;">Total Correct</p>
Nutrition Facts		% Daily Value*																																						
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Summary: NVS¹⁸

Description	<ul style="list-style-type: none"> 6-item assessment measuring reading comprehension of a nutrition label Average administration time: 3-6 min
Measurement	<ul style="list-style-type: none"> 0-4: Patient is likely to have low health literacy 5-6: Patient is unlikely to have low health literacy
Strengths	<ul style="list-style-type: none"> Tests for numeracy, reading ability, and reading comprehension Available in English and Spanish Correlates with TOFHLA May be more sensitive to patients with marginal health literacy than other functional health literacy assessments
Limitations	<ul style="list-style-type: none"> May overestimate the percent of patients with low health literacy due to its specificity Does not differentiate well between adequate and marginal health literacy
Location	<ul style="list-style-type: none"> Available online: http://www.pfizerhealthliteracy.com/physiciansproviders/newest-vital-sign.html

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Short Assessment of Health Literacy¹⁹

- A new instrument consisting of comparable tests in English and Spanish
- Good reliability and validity in both languages
- **18 terms**, for each term a key word with a related meaning and a distractor word with an unrelated meaning are provided
- Tests reading comprehension and pronunciation
- Average administration time: **3-5 minutes**

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Answer Key: SAHL – English²⁰

1. kidney	urine	fever	don't know
2. occupation	work	education	don't know
3. medication	instrument	treatment	don't know
4. nutrition	healthy	soda	don't know
5. miscarriage	loss	marriage	don't know
6. infection	plant	virus	don't know
7. alcoholism	addiction	recreation	don't know
8. pregnancy	birth	childhood	don't know
9. seizure	dizzy	calm	don't know
10. dose	sleep	amount	don't know
11. harmonies	growth	harmony	don't know
12. abnormal	different	similar	don't know
13. directed	instructions	decision	don't know
14. nerves	bored	anxiety	don't know
15. constipation	blocked	loose	don't know
16. diagnosis	evaluation	recovery	don't know
17. hemorrhoids	veins	heart	don't know
18. syphilis	contraception	condom	don't know

Correct answers in **bold**

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Summary: SAHL-S&E²¹

Description	<ul style="list-style-type: none"> • New instrument consisting of comparable tests in English and Spanish • 18 terms, for each term a key word with a related meaning and a distractor word with an unrelated meaning are provided • Average administration time: 3-5 min
Measurement	<ul style="list-style-type: none"> • 0-14: Low health literacy • 15-18: Patient is unlikely to have low health literacy
Strengths	<ul style="list-style-type: none"> • Tests for reading comprehension and pronunciation • Good reliability and validity in both English and Spanish
Limitations	<ul style="list-style-type: none"> • Does not measure numeracy
Location	<ul style="list-style-type: none"> • Available online: https://www.ahrq.gov/health-literacy/quality-resources/tools/literacy/index.html

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Short Assessment of Health Literacy for Spanish-Speaking Adults (SAHLSA-50)²¹

- A validated, **50-item** health literacy assessment tool
- Designed to assess the ability of Spanish-speaking adults to read and understand common medical terms
- Average administration time: **20 minutes**
- Based on the REALM assessment tool, known as the most easily administered tool for assessing the health literacy of English-speaking adults

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Partial Answer Key – SAHLSA-50

Stem	Key or Distractor	"No se" (Don't know)
1. prostata	glándula	...circulación
2. empleo	trabajo	...educación
3. mensual	mensual	...diario
4. gripa	señal	...enfriamiento
5. antepasado	padre	...hermano
6. comida	cena	...desayuno
7. alcoholismo	adicción	...recreo
8. grasa	manteca	...aceite
9. saliva	respirar	...sudar
10. catatona	energía	...agotamiento
11. osteoporosis	hueso	...músculo
12. depresión	apetito	...sentimientos
13. estornudo	bloqueo	...cough
14. empujón	partido	...enfriamiento
15. incendio	familia	...vecinos
16. pastilla	tableta	...gotitas
17. testículo	espermatozoide	...ovario
18. resaca	resaca	...resaca
19. ojo	ojo	...nariz
20. irritación	irritación	...dolor

Correct answers in **bold**

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Summary: SAHLSA-50²⁰⁻²¹

Description	<ul style="list-style-type: none"> • 50-item health literacy assessment tool, designed to assess the ability of Spanish-speaking adults to read and understand common medical terms • Average administration time: 20 min
Measurement	<ul style="list-style-type: none"> • 0-37: Inadequate health literacy • 38-50: Adequate health literacy
Strengths	<ul style="list-style-type: none"> • Validated • Based on REALM - the most easily administered tool for assessing the health literacy of English-speaking adults
Limitations	<ul style="list-style-type: none"> • Does not measure numeracy • Long administration time
Location	<ul style="list-style-type: none"> • Available online: https://www.ahrq.gov/health-literacy/quality-resources/tools/literacy/index.html

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Medical Term Recognition Test (METER)²²⁻²³

- Initial findings show this test is a quick and practical measure of health literacy for use in clinical settings
- Test consists of a list containing:
 - Some **real** medical words (e.g., words that have to do with body parts or functions, kinds of diseases, or things that can make your health better or worse)
 - Some words that look or sound like medical words but are **not** actual words
- Average administration time: 2-3 minutes

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METER – Sample Items

Instructions: As you read through the list, put an "X" next to the items that you know are real words. You should not guess. Only put an "X" next to an item if you're sure it's a real word.

<input type="checkbox"/> Irrity	<input type="checkbox"/> Kidney
<input type="checkbox"/> Arthritis	<input type="checkbox"/> Emergency Patient
<input type="checkbox"/> Obesity	<input type="checkbox"/> Menopause
<input type="checkbox"/> Flu	<input type="checkbox"/> Diagnosis
<input type="checkbox"/> Behaviose	<input type="checkbox"/> Depretion
<input type="checkbox"/> Syphilis	<input type="checkbox"/> Jaundice
<input type="checkbox"/> Potassium	<input type="checkbox"/> Gallbladder
<input type="checkbox"/> Hormones	<input type="checkbox"/> Miscarriage
<input type="checkbox"/> Nerves	<input type="checkbox"/> Hepatitis
<input type="checkbox"/> Plik	<input type="checkbox"/> Astiringe
<input type="checkbox"/> Rection	<input type="checkbox"/> Nutral
<input type="checkbox"/> Blout	<input type="checkbox"/> Asthma
<input type="checkbox"/> Boweling	<input type="checkbox"/> Inflammatory
<input type="checkbox"/> Exercise	<input type="checkbox"/> Anemia
<input type="checkbox"/> Pustule	<input type="checkbox"/> Allagren
<input type="checkbox"/> Cerpes	<input type="checkbox"/> Progrincy
	<input type="checkbox"/> Stress
	<input type="checkbox"/> Elargic

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Summary: METER²²⁻²³

Description	<ul style="list-style-type: none"> Test consists of a list containing some real medical words and some words that look or sound like medical words but are not actual words Average administration time: 2-3 minutes
Measurement	<ul style="list-style-type: none"> 0-20: Low health literacy 21-34: Marginal health literacy 35-40: Functional health literacy
Strengths	<ul style="list-style-type: none"> Initial findings show this test is a quick and practical measure of health literacy for use in clinical settings
Limitations	<ul style="list-style-type: none"> Does not measure numeracy Test was validated using a predominately white (93%) sample
Location	<ul style="list-style-type: none"> Available online: https://healthliteracy.bu.edu/meter

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Brief Health Literacy Screening Tool (BRIEF)²⁴⁻²⁵

- 4-item** questionnaire developed and evaluated by Chew et al.
- Must consider patient's shame and stigma related to low literacy or low health literacy when answering the questions
- Presence of family or friends may alter accuracy
- Do NOT administer the test with a medical interpreter
 - This test has **not** been **validated** for use with a medical interpreter
- Average administration time: **2 minutes**

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BRIEF – Screener Question²⁴⁻²⁵

Please circle the answer that best represents your response.

1. How often do you have someone help you read hospital materials? 1. Always 2. Often 3. Sometimes 4. Occasionally 5. Never	1. How often do you have a problem understanding what is told to you about your medical condition? 1. Always 2. Often 3. Sometimes 4. Occasionally 5. Never
2. How often do you have problems learning about your medical condition because of difficulty understanding written information? 1. Always 2. Often 3. Sometimes 4. Occasionally 5. Never	1. How confident are you filling out medical forms by yourself? 1. Not at all 2. A little bit 3. Somewhat 4. Quite a bit 5. Extremely

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Summary: BRIEF²⁴⁻²⁵

Description	<ul style="list-style-type: none"> 4-item questionnaire Average administration time: 2 minutes
Measurement	<ul style="list-style-type: none"> 2-12: Inadequate health literacy 13-16: Marginal health literacy 17-20: Adequate health literacy
Strengths	<ul style="list-style-type: none"> Quick administration time
Limitations	<ul style="list-style-type: none"> Patient's sense of shame and stigma related to low literacy or low health literacy may affect responses/Self reporting bias Not validated for use with medical interpreters
Location	<ul style="list-style-type: none"> Available online: https://healthliteracy.bu.edu/brief

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Brief Estimate of Health Knowledge and Action — HIV Version (BEHKA-HIV)²⁶⁻²⁷

- **8-item** assessment of patient knowledge and action related to **HIV** treatment
- Many patients with HIV were interviewed to develop this tool
- Researchers compared BEHKA-HIV with Rapid Estimate of Adult Literacy in Medicine (REALM)
 - BEHKA-HIV demonstrated **high** internal consistency and construct **validity**
- Average administration time: **3 minutes**

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BEHKA-HIV²⁶

Part I: Knowledge—"We would like to know if patients are familiar with two HIV terms: a CD4 count and viral load. Would you mind if I ask you a few questions about that? Ok..."

1a. What is a *CD4 count*?

Determine if correct

1b. If 1a is correct, is the goal of treatment to make the *CD4 count* go up or down?
UP [1] DOWN [0]

2a. What is a *viral load*?

Determine if correct

2b. If 2a is correct, is the goal of treatment to make the *viral load* go up or down?
UP [0] DOWN [1]

3. What medicines are you currently taking to treat HIV?
Respondent must identify all medications in HAART regimen to be correct
CORRECT [1] INCORRECT [0] DON'T KNOW [0]

Part II: Action—"Please tell me if you agree, are not sure, or disagree with these 5 statements..."

1. I don't take my medicines when they make me feel bad.	AGREE [0]	NOT SURE [0]	DISAGREE [1]
2. I don't take my medicines when I am too tired.	AGREE [0]	NOT SURE [0]	DISAGREE [1]
3. I don't take my medicines when I am feeling down or low.	AGREE [0]	NOT SURE [0]	DISAGREE [1]
4. I don't take my medicines because it tastes bad.	AGREE [0]	NOT SURE [0]	DISAGREE [1]
5. I don't take my medicines when I feel good.	AGREE [0]	NOT SURE [0]	DISAGREE [1]

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Summary: BEHKA-HIV²⁶⁻²⁷

Description	<ul style="list-style-type: none"> • An 8-item assessment of HIV knowledge and treatment action (3 items associated with knowledge; 5 items associated with action) • The knowledge subscale measures a patient's capacity to understand health information, while the action subscale measures a patient's ability to make actionable decisions to obtain health information • Average administration time: 3 minutes
Measurement	<ul style="list-style-type: none"> • 0-3: Low health literacy • 4-5: Marginal health literacy • 6-8: Adequate health literacy
Strengths	<ul style="list-style-type: none"> • May better represent health literacy for HIV patients than more general tools measuring reading ability in a health context • Scores on BEHKA-HIV were significantly associated with self reported medication adherence
Limitations	<ul style="list-style-type: none"> • Not a direct test of functional health literacy in terms of reading ability and reading comprehension • Further validation needed
Location	<ul style="list-style-type: none"> • Osborn CY, Davis TC, Bailey SC, and Wolf MS. Health Literacy in the Context of HIV Treatment: Introducing the Brief Estimate of Health Knowledge and Action (BEHKA)-HIV Version. <i>AIDS Behavior</i>. 2008.

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Single Item Literacy Screener (SILS)²⁸

- **Single** item designed to assess patient's reading ability – a critical component of health literacy
- Goal: to identify patients who need help reading health-related materials
- Research shows tool performs moderately well in terms of ruling out limited reading ability as a factor affecting health outcomes
- Can be used to identify **at-risk** individuals as candidates for more in-depth health literacy screening

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Summary: SILS²⁸


Description	<ul style="list-style-type: none"> • Single item used to identify adults who may need help reading health-related materials • "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"
Measurement	<ul style="list-style-type: none"> • 1-Never, 2-Rarely, 3-Sometimes, 4-Often, 5-Always • Scores greater than 2 indicate some difficulty reading health-related materials
Strengths	<ul style="list-style-type: none"> • Practical for use in clinical practice • Direct assessment of need versus assessment of skill • Simpler than an estimate based on demographics
Limitations	<ul style="list-style-type: none"> • False negatives may occur due to participants not recognizing that they need help with reading, feeling ashamed, or not understanding the question
Location	<ul style="list-style-type: none"> • Morris NS, MacLean CD, Chew LD, and Littenberg B. The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. <i>BMC Family Practice</i>. 2006; 7(21). doi: 10.1186/1471-2296-7-21

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Additional Health Literacy Assessment Tools

- REALM-SF, REALM-VS, REALM99, REAL-G, HKREALD-30
- Functional Health Literacy Test (FHLTs)
- Health Literacy Skills Instrument (HLSI)
- Health Literacy Assessment Using Talking Touchscreen Technology (Health LITT)



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Condition-specific Health Literacy Assessment Tools

- Literacy Assessment for **Diabetes** (LAD)
- **Diabetes** Numeracy Test (DNT-15)
- The Food Label Literacy for Applied **Nutrition** Knowledge questionnaire (FLLANK)
- **Asthma** Numeracy Questionnaire (ANQ)
- The Numeracy Understanding in Medicine Instrument (NUMi)
- HBP-Health Literacy scale (HBP-HLS)
- **Spanish** Parental Health Literacy Activity Test (PHLAT) Spanish, PHLAT-8
- Literacy Measure for patients with **HIV**

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Comparison of Health Literacy Tools

	REALM	TOFHLA STOFHLA	BRIEF (SILS)	SAHLSA	NVS	METER	FHLTs	HLSI	Health LIT
Constructs Measured	Word recognition & pronunciation of medical terms	Reading comprehension & numeracy skills	Reading and verbal comprehension	Word recognition medical terms	Reading and comprehension of nutrition label	Word recognition of medical terms	Reading comprehension	Prose, document, oral & internet based info seeking	Prose, document, quantitative
Year Published	1991-1993	1995-1999	2004-2009	2006-10	2007	2009	2009	2010/12	2011
Administration	3-7 long	22 long	1-2	3-6 long	3-4	3	3	>10 long	18
Time (minutes)	2 short	7 short		3 short				5 short	
Number of Items	786 items	1750 items 336 items	4 items	50 items 18 items	6 items	70 items	21 items	25 items 10 items	30 items
Performance based	YES	YES		YES	YES	YES	YES	YES	YES
Self administered			YES			YES		YES	YES
Spanish		YES	YES	YES	YES				YES
Long distance			YES			YES		YES	With Touch Screen Access

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Comparison of Health Literacy Tools Cont'd

	REALM	TOFHLA STOFHLA	BRIEF (SILS)	SAHLSA	NVS	METER	FHLTs	HLSI	Health LIT
Communication, verbalization	✓			✓		✓			
Comprehension, reading, problem solving		✓	✓		✓		✓	✓	✓
Numeracy, quantitative		✓	✓					✓	✓
Health Information seeking								✓	
Function			✓		✓			✓	✓
Decision making, critical thinking		✓			✓			✓	✓
Confidence, self efficacy			✓						
Need for assistance			✓					✓	

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OTHER RESOURCES AND TECHNIQUES FOR ADDRESSING LOW HEALTH LITERACY

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3 Questions²⁹

- Two studies investigated the utility of three questions in detecting limited health literacy:
 1. How often do you have **problems** learning about your medical condition because of difficulty understanding written information?
 2. How often do you have someone **help** you **read** hospital materials?
 3. How confident are you **filling out** medical forms by yourself?
- The **5** possible responses: always, often, sometimes, occasionally, or never
- Answers of sometimes, occasionally and never indicate low health literacy
- Responses to each question corresponded to health literacy scores obtained via S-TOFHLA and REALM
- Study conducted using a sample of primary care patients from 4 VA Medical Centers, may not be generalizable

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Schooling, Opinion, Support: SOS Mnemonic³⁰

- Study found that an individual's highest level of **SCHOOLING**, self-reported **OPINION** of their reading ability, and solicitation of **SUPPORT** when reading health-related materials all independently **predicted** an S-TOFHLA score indicating low health literacy
- Results suggested the use of all **three items** is superior to the use of any one individual item
- Results based on a sample of patients receiving diabetes treatment at one academic family practice center – may **not** be generalizable
- Patients knew they were receiving a reading test and may have been less likely to conceal a reading problem
- **Not validated** for use with the general population

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Ask Me 3: A Tool for Patients with Low Health Literacy

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Ask Me 3: Instructions for Patients³¹

ASK THESE 3 QUESTIONS WHEN . . .

- You see a doctor, nurse, pharmacist, or other health care provider
- You prepare for a medical test or procedure
- You get your medicine

- 1. What is my main problem?**
- 2. What do I need to do?**
- 3. Why is it important for me to do this?**

What if I ask and still don't understand?

- Let your doctor know if you **still don't** understand what you need.
- You might say, "This is new to me. Will you please **explain** that to me one more time?"

Who needs to ask 3?

- Everyone who wants help with health information. You are not alone if you find things confusing at times.

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Key Differences Between Health Literacy Tools

- Instruments vary from screening items to performance-based measures
- Tools vary in their approach to operationalizing "health literacy" as a measurable concept
- Administration styles vary
- Time and resources needed vary
- Scoring, ranges, and levels vary
- Languages vary

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Research: Measurement Variations

- Research demonstrating variations in measurement between health literacy assessment tools is limited
- Griffin et al, 2010³²:
 - Estimates of poor health literacy varied by the assessment tool used, especially after adjusting for non-response bias
 - STOFHLA: 8% of respondents had "inadequate skills", 7% had "marginal skills"
 - REALM: 4% of respondents had "6th grade skills (inadequate)", 17% had "7th grade skills (marginal)"
 - Adjusting for non-response bias:
 - STOFHLA: 9.3% - inadequate, 12% - marginal
 - REALM: 6% - 6th grade/inadequate, 34% - 7th grade/marginal

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Research: Measurement Variations (Cont'd)

- Haun et al, 2012³³:
 - Correlation among tools was positive, with the strongest association between STOFHLA and REALM
 - Measurement categories and categories for associated factors (e.g., gender, race) varied from tool to tool
 - REALM and BRIEF categorized the mean score as "marginal" health literacy, STOFHLA categorized the mean score as "adequate" health literacy
 - Tools concurred most often when categorizing respondents as having "adequate" health literacy skills

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Measurement Variation in Diverse Populations

- Haun et al, 2012³³:
 - Factors associated with health literacy varied depending on the tool used
 - Minority status was associated with low health literacy on REALM and STOFHLA, but not BRIEF
 - Education was associated with low health literacy on REALM and BRIEF, but not STOFHLA
 - Old age was associated with low health literacy on STOFHLA and BRIEF, but not REALM
 - Gender was not significantly associated with health literacy in this study, but some research suggests there is an association between health literacy and gender

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Measurement Variation – Is There a Best Option?

- Until measures and constructs related to culture, language, and associated outcomes are definitively understood, researchers, clinicians, public health practitioners, and administrators need to identify **best** options
- Align measures with context:
 - Resources
 - Population
 - Disease
 - Language
 - Age
 - Etc.
- Use **different** tools for different scenarios

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